

Characteristics of an Ambulatory Palliative Care Clinic for HIV-Infected Patients

Brian A. Perry, BA,¹ Andrew O. Westfall, MS,² Elizabeth Molony, BS,¹ Rodney Tucker, MD, MMM,³ Christine Ritchie, MD, MSPH,^{5,6} Michael S. Saag, MD,⁴ Michael J. Mugavero, MD, MHSc,⁴ and Jessica S. Merlin, MD, MBA^{3,4}

Abstract

Background: Many HIV-infected patients in the current treatment era have substantial symptom burden, but few HIV palliative care clinics have been described. Our objective was to describe the University of Alabama at Birmingham (UAB) HIV palliative care clinic (HPCC) and compare it to the overall HIV clinic.

Methods: We conducted a chart review of patients referred to the HPCC between April 2008 and June 2011. We evaluated the reason for referral and other issues addressed during palliative care visits. Patient Reported Outcome (PRO) data was used to assess depression (PHQ-9), anxiety (PHQ-A), and substance abuse (ASSIST).

Results: Among 124 patients, mean age was 44 (range 27–64), and median CD4 count was 352 cells/mm³ (IQR 209–639). Depression (43, 35%), anxiety (40, 32%), and current 8 (7%) or prior 68 (56%) substance abuse occurred at higher rates than in the overall HIV clinic ($p < 0.05$). Pain was the most common reason for referral (118, 95%); most was chronic (113, 90%) and included back pain (26, 21%) and neuropathic pain (15, 12%). Other problems commonly addressed by the palliative team included nonpain symptoms such as depression (39, 48%) and anxiety (17, 21%), insomnia (25, 30%), and constipation (26, 32%).

Conclusions: This is the first description of a palliative care clinic embedded within an HIV primary care clinic in a developed country that sees patients at all stages of illness. Chronic pain and nonpain symptom management in patients with psychiatric and substance abuse comorbidities are important components of ambulatory palliative care for HIV-infected patients.

Introduction

IN THE EARLY YEARS of the epidemic, HIV carried a poor prognosis. The development of “highly active antiretroviral therapy” in the 1990s altered the course of the epidemic, and HIV became a chronic disease. In the current treatment era, those successfully treated with antiretroviral therapy have a near-normal life expectancy.¹

As patients with HIV live longer, the focus of HIV care and research has shifted from finding the best antiretroviral regimen to managing highly prevalent comorbid conditions, such as cardiovascular disease, cirrhosis, and non-AIDS-defining malignancies, and optimizing quality of life.² In this chronically medically ill patient population, there is evidence that pain and nonpain symptoms are common. Estimates of pain prevalence in HIV-infected patients in the current treatment

era range from 39%–55%;^{3–10} however, the etiology of this pain has not been well characterized. Also, one recent study found that HIV-infected patients experience an average of eight nonpain physical and psychological symptoms, including lack of energy, numbness in the hands and feet, worrying, and feeling sad.⁹ As many as half of HIV-infected patients suffer from psychiatric or substance abuse comorbidities.^{11–14}

Despite the substantial pain and symptom burden experienced by HIV-infected patients in the current treatment era, only two HIV-focused palliative care clinics have been described, which both focus on AIDS patients at the end of life.^{15,16} Our objective was to describe the University of Alabama at Birmingham (UAB) HIV palliative care clinic (HPCC), which is embedded within an HIV primary care clinic and sees patients at all stages of illness, and compare it

¹School of Medicine, ²Department of Biostatistics, School of Public Health, ³Division of Gerontology, Geriatrics, and Palliative Care, Department of Medicine, ⁴Division of Infectious Diseases, Department of Medicine, University of Alabama at Birmingham, Birmingham, Alabama.

⁵Division of Geriatrics, Department of Medicine, University of California at San Francisco, San Francisco, California.

⁶Jewish Home of San Francisco Center for Research on Aging, San Francisco, California.

Accepted February 14, 2013.

to the overall clinic cohort. We hypothesized that patients referred to the HPCC would be more likely to have psychiatric, substance abuse, and medical comorbidities than the general clinic population.

Methods

The 1917 Clinic at UAB is an HIV patient centered medical home that serves 2000 active patients and includes HIV primary care providers, psychiatric care, psychologists, substance abuse counselors, numerous medical subspecialty providers, a pharmacy, and a laboratory under one roof. Most patients at the 1917 Clinic are enrolled in an ongoing prospective cohort study of nearly 2000 participants that includes collection of Patient Reported Outcome questionnaires (PROs) on a variety of subjects including depression, anxiety, substance abuse, and routine demographic and clinical data.¹⁷

Within this primary care clinic and cohort, the HPCC was established in 2004. It has grown into a clinic that includes an attending, a physician assistant, and one or two palliative medicine fellows per session. It sees up to twelve patients one half-day per week. Patients must be referred to the HPCC by primary care providers within the 1917 Clinic. We conducted a chart review of patients who were referred to the HPCC between April 2008 and June 2011, had a PRO within one year of the referral date, were 19 years old at the first PRO during the study period, and were scheduled for their first HPCC appointment during the study period. Two trained study staff members reviewed primary care and palliative care notes, and a palliative care expert adjudicated all discrepancies. Each chart was evaluated for the reason for referral; if pain was the reason for the referral; whether the pain was chronic; whether the patient was on opioids at the time of referral,¹⁸ whether the patient was ever referred to hospice; and whether the patient was subsequently discharged from hospice.

Additionally, we compared the HPCC to the overall 1917 Clinic HIV cohort. We applied the following inclusion criteria for the comparison group: an arrived primary care visit in the study period (because an arrived primary care visit is a prerequisite to referral to the HPCC); never referred to the HPCC (regardless of whether the patient ever went or not); at least 19 years old at first arrived primary care visit in the study period; and PRO within ±365 days of the first arrived primary care visit in the study period.

For both groups, demographic and diagnosis data were obtained from the date of the visit or the value closest to the referral date, and PRO data were obtained from within ±365 days of the referral date. Viral loads and CD4+ T cell counts were obtained within -210, +14 days from the HPCC referral date/first arrived primary care visit. Depression was defined as a PHQ-9 ≥10, anxiety as PHQ-9A with anxiety symptoms or panic,^{17,19,20} and substance abuse measured using the ASSIST.^{17,21} Comparison was performed using the Wilcoxon rank sum for continuous variables and chi square for categorical variables. In addition, we compared patients who no-showed to the palliative care clinic with patients who had ≥1 arrived HPCC visit; and we compared patients with 1 arrived HPCC visit to those with ≥1 HPCC visit. This study was approved by the institutional review board of the University of Alabama at Birmingham.

Results

During the study period, 137 patients were referred to the HPCC for the first time, of whom 124 patients met the inclusion criteria. Among these 124 patients, mean age was 44 (range 27–64); 37 (30%) patients were female, 56 (46%) were nonwhite, and 106 (85%) were publicly insured or uninsured. The median CD4 count was 352 cells/mm³ (IQR 209–639), and 69 (56%) had undetectable (<200) viral loads. Based on PRO data, many reported depression (43, 35%) or anxiety (40, 32%) and current 8 (7%) or prior 68 (56%) substance abuse. Patients referred to the HPCC were more likely than patients in the overall cohort to have IV drug use as their transmission risk factor, public insurance, symptoms of pain, depression, anxiety, a history of substance abuse, an arrived psychiatry or psychology visit, impairment in physical function, or one of several medical comorbidities (see Table 1). Pain was the most common primary reason for referral (117, 94%); the majority of pain was chronic (107, 91%). The most common primary

TABLE 1. COMPARISON BETWEEN THE HPCC AND OVERALL CLINIC

Variable	HPCC (N=124)	Overall 1917 clinic (N=1368)
Age (median, IQR)*	44 (38–49)	42 (34–49)
Nonwhite race	56 (46%)	754 (56%)
Female	37 (30%)	309 (23%)
Transmission risk Factor*		
Heterosexual	45 (36%)	472 (35%)
Intravenous drug use	29 (23%)	102 (7%)
Men who have sex with men	49 (40%)	737 (54%)
Other/unknown	1 (1%)	57 (4%)
Insurance*		
Private	17 (14%)	538 (39%)
Public	72 (58%)	346 (25%)
None	35 (28%)	484 (35%)
CD4 (median, IQR)	352 (209–639)	407 (231–608)
VL undetectable	69 (56%)	652 (48%)
Pain	96 (78%)	427 (32%)
Depression (PHQ-9 ≥ 10)*	43 (35%)	208 (15%)
Anxiety*	40 (33%)	247 (18%)
Substance abuse*		
current	8 (7%)	116 (9%)
prior	68 (56%)	375 (28%)
never	46 (38%)	864 (64%)
Psychiatry/psychology visit*	94 (76%)	506 (37%)
Impaired mobility*	58 (47%)	199 (15%)
Impaired self-care*	14 (11%)	48 (4%)
Impaired usual activities*	63 (51%)	214 (16%)
Comorbidities		
COPD*	11 (8.9%)	39 (2.9%)
Sleep disorders*	59 (48%)	427 (31%)
Cardiovascular*	14 (11%)	89 (7%)
Depression*	84 (68%)	645 (47%)
Anxiety*	42 (34%)	323 (27%)
Bipolar*	13 (11%)	42 (3%)

*p < 0.05.

COPD, chronic obstructive pulmonary disease; HPCC, HIV palliative care clinic; IQR, interquartile range; PHQ-9A, anxiety symptoms, panic; VL, viral load.

causes of pain were back pain (26, 21%) and neuropathic pain (15, 12%); the remainder included pain in other locations such as leg, hip, shoulder, neck, and joints (<10% each). Half of patients (62, 50%) were on opioids at the time of referral. Nonpain reasons for referral were end-of-life care (5, 4%) and fatigue (1, 1%).

Forty-two patients (34%) did not arrive to ≥ 1 HPCC visit; of these, 7 died prior to the scheduled visit date. We compared characteristics of patients who did not arrive to ≥ 1 visit with patients who arrived to ≥ 1 visit; there were no statistically significant differences. Eighty-two patients (66%) arrived to ≥ 1 palliative care visit. Of these, many patients came to > 1 visit during the study period (median number of visits 3, IQR=2–6, range 1–12). We also compared characteristics of patients who arrived to 1 visit with patients who arrived to > 1 visit. Patients who arrived to 1 visit were more likely to have private insurance and were more likely to be in the transmission risk category of men who have sex with men than patients who arrived to > 1 visit ($p < 0.05$); otherwise, there were no statistically significant differences. The most common primary problem addressed by palliative care was pain (80, 96%). Other problems commonly addressed by the palliative team included nonpain symptoms such as depression (41, 50%) and anxiety (17, 21%), insomnia (27, 33%), and constipation (26, 32%). Nonpain symptoms addressed in fewer than five patients were wide-ranging and included diarrhea, edema, fatigue, muscle spasms, nausea, pruritus, sexual dysfunction, and shortness of breath. Of eight patients (6%) who were on hospice, four were discharged from hospice.

Discussion

To our knowledge, this is the first study to describe an HIV/palliative care clinic in a developed country embedded within an HIV patient-centered medical home that sees patients at all stages of illness, not only at the end of life. The HPCC addresses causes of morbidity in HIV-infected patients: chronic pain as well as numerous nonpain symptoms. In this study the most common cause of pain was chronic low back pain, which is also very common in general primary care settings.

Recent data from the 1917 Clinic cohort ($N=2000$) found that 34% of patients reported pain “today,” which provides a rough estimate of chronic pain prevalence.¹⁰ This suggests that the 124 patients referred to the HPCC make up only a fraction of the total number of patients with chronic pain at 1917. Similar to any other specialty clinic, it is likely that patients who are referred to the HPCC are more clinically complex than patients who are not referred. It is notable that one-third of those referred had depression, one-third had anxiety, and half had a history of substance abuse, rates that are significantly higher than seen in the clinic at large. Since HIV primary care providers may feel uncomfortable addressing chronic pain, especially in the setting of substance abuse,²² and perhaps also in the setting of psychiatric illness, palliative care practitioners who provide ambulatory services to HIV-infected patients may be sought for their expertise in caring for these complex patients.

As palliative care shifts its focus from end-of-life care farther upstream to patients with chronic diseases, ambulatory palliative care programs may begin to see patients with

chronic pain. Chronic pain management has not been part of the traditional palliative care skill set.²³ Palliative care providers may need to learn chronic pain management techniques such as motivational interviewing, cognitive behavioral therapy, and opioid risk mitigation strategies, and become comfortable with basic management of chronic psychiatric conditions such as depression and anxiety.

Although chronic pain was the primary reason for referral and the primary problem addressed after referral, it was far from the only issue addressed during palliative care visits. It seems likely that pain was a “foot in the door” to the HPCC. Once enrolled in the HPCC, the palliative care approach was employed of caring for the whole patient, including numerous physical and psychological symptoms. Many patients were seen repeatedly—as many as 12 times over a 3-year period—to care for their varied needs.

This study has limitations. It included data only from one clinic, and had a small sample size. The population referred to the HPCC has a referral bias: It is likely that only the most complex cases are referred. Also, due to methodologic limitations, this study did not seek to evaluate the impact of palliative care on outcomes in HIV-infected patients. For example, we were only able to assess whether patients were on opioid therapy or not, but did not have consistent information about other prescribing, or referral to external providers. Although we have very crude data on patient reported outcome measures, we do not have pre-post data relative to the date of the first HPCC visit. However, as the first study that describes an HIV palliative care clinic in detail and compares it to an overall community based HIV cohort, the study makes an important contribution to the literature in this area.

In sum, chronic pain was the most common reason for referral to this HIV palliative care clinic. Pain was just one of a large number of physical and psychological symptoms addressed by the palliative care team. Models for integration of palliative care into HIV primary care and opportunities for collaborative research between HIV palliative care clinics should be explored.

Author Disclosure Statement

No competing financial interests exist.

References

1. Collaboration ATC: Life expectancy of individuals on combination antiretroviral therapy in high-income countries: A collaborative analysis of 14 cohort studies. *Lancet* 2008;372:293–299.
2. Saag MS: HIV now firmly established in the Middle Ages. *Clin Infect Dis* 2011;53:1140–1142.
3. Newsham G, Bennett J, Holman S: Pain and other symptoms in ambulatory HIV patients in the age of highly active antiretroviral therapy. *J Assoc Nurses AIDS Care* 2002;13:78–83.
4. Lee KA, Gay C, Portillo CJ, et al.: Symptom experience in HIV-infected adults: A function of demographic and clinical characteristics. *J Pain Symptom Manage* 2009;38:882–893.
5. Richardson JL, Heikes B, Karim R, Weber K, Anastos K, Young M: Experience of pain among women with advanced HIV disease. *AIDS Patient Care STDS* 2009;23:503–511.

6. Aouizerat BE, Miaskowski CA, Gay C, et al.: Risk factors and symptoms associated with pain in HIV-infected adults. *J Assoc Nurses AIDS Care* 2010;21:125–133.
7. Cervia LD, McGowan JP, Weseley AJ: Clinical and demographic variables related to pain in HIV-infected individuals treated with effective, combination antiretroviral therapy (cART). *Pain Med* 2010;11:498–503.
8. Harding R, Lampe FC, Norwood S, et al.: Symptoms are highly prevalent among HIV outpatients and associated with poor adherence and unprotected sexual intercourse. *Sex Transm Infect* 2010;86:520–524.
9. Merlin JS, Cen L, Praestgaard A, et al.: Pain and physical and psychological symptoms in ambulatory HIV patients in the current treatment era. *J Pain Symptom Manage* 2012;43:638–645.
10. Merlin JS, Westfall AO, Raper JL, et al.: Pain, mood, and substance abuse in HIV: Implications for clinic visit utilization, art adherence, and virologic failure. *J Acquir Immune Defic Syndr* 2012;61(2):164–170.
11. Gaynes BN, Pence BW, Eron JJ, Miller WC: Prevalence and comorbidity of psychiatric diagnoses based on reference standard in an HIV+ patient population. *Psychosom Med* 2008;70:505–511.
12. Pence BW, Miller WC, Whetten K, Eron JJ, Gaynes BN: Prevalence of DSM-IV-defined mood, anxiety, and substance use disorders in an HIV clinic in the Southeastern United States. *J Acquir Immune Defic Syndr* 2006;42:298–306.
13. Orlando M, Burnam MA, Beckman R, et al.: Re-estimating the prevalence of psychiatric disorders in a nationally representative sample of persons receiving care for HIV: Results from the HIV Cost and Services Utilization Study. *Int J Methods Psychiatr Res* 2002;11:75–82.
14. Galvan FH, Burnam MA, Bing EG: Co-occurring psychiatric symptoms and drug dependence or heavy drinking among HIV-positive people. *J Psychoactive Drugs* 2003;35 Suppl 1:153–160.
15. Ruiz M, Cefalu C: Palliative care program for human immunodeficiency virus-infected patients: Rebuilding of an academic urban program. *Am J Hosp Palliat Care* 2011;28:16–21.
16. Karus D, Raveis VH, Alexander C, et al.: Patient reports of symptoms and their treatment at three palliative care projects servicing individuals with HIV/AIDS. *J Pain Symptom Manage* 2005;30:408–417.
17. Kozak MS, Mugavero MJ, Ye J, et al.: Patient reported outcomes in routine care: Advancing data capture for HIV cohort research. *Clin Infect Dis* 2012;54:141–147.
18. Hansen L, Penko J, Guzman D, Bangsberg DR, Miaskowski C, Kushel MB: Aberrant behaviors with prescription opioids and problem drug use history in a community-based cohort of HIV-infected individuals. *J Pain Symptom Manage* 2011;42:893–902.
19. Löwe B, Gräfe K, Zipfel S, et al.: Detecting panic disorder in medical and psychosomatic outpatients: Comparative validation of the Hospital Anxiety and Depression Scale, the Patient Health Questionnaire, a screening question, and physicians' diagnosis. *J Psychosom Res* 2003;55: 515–519.
20. Kroenke K, Spitzer RL, Williams JB: The PHQ-9: Validity of a brief depression severity measure. *J Gen Intern Med* 2001;16:606–613.
21. Newcombe DA, Humeniuk RE, Ali R: Validation of the World Health Organization Alcohol, Smoking and Substance Involvement Screening Test (ASSIST): Report of results from the Australian site. *Drug Alcohol Rev* 2005; 24:217–226.
22. Lum PJ, Little S, Botsko M, et al.: Opioid-prescribing practices and provider confidence recognizing opioid analgesic abuse in HIV primary care settings. *J Acquir Immune Defic Syndr* 2011;56(Suppl 1):S91–S97.
23. Merlin JS, Childers J, Arnold RM: Chronic pain in the outpatient palliative care clinic. *Am J Hosp Palliat Care* 2012. [Epub ahead of print.]

Address correspondence to:
Jessica S. Merlin, MD, MBA
E-mail: jmerlin@uab.edu